

Community Health Workers as Trust Builders and Healers: A Cohort Study in Primary Care

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ABSTRACT

PURPOSE Improving patients' self-care for chronic disease is often elusive in the context of social deprivation. We evaluated whether a practice-integrated community health worker (CHW) intervention could encourage effective long-term self-management of type 2 diabetes mellitus (T2DM).

METHODS This cohort study, in a safety-net primary care practice, enrolled patients with uncontrolled T2DM and psychosocial risk factors. Patients were identified through a practice diabetes registry or by clinicians' referrals. The CHWs engaged patients in trust building and sensemaking to understand their social context, identify goals, navigate health care, and connect to community resources. Primary outcome was progress through 3 prospectively defined stages of self-care: outreach (meeting face-to-face); stabilization (collaborating to address patients' life circumstances); and self-care generativity (achieving self-care competencies). Secondary outcomes were change in hemoglobin A_{1c} (HbA_{1c}) and need for urgent care, emergency department, or hospital visits.

RESULTS Of 986 participating patients, 27% remained in outreach, 41% progressed to stabilization, and 33% achieved self-care generativity. Repeated measures ANOVA demonstrates an overall decline in HbA_{1c}, without group differences, through the 4th HbA_{1c} measurement (mean follow-up 703 days). Beginning at the 5th HbA_{1c} measurement (mean 859 days), the self-care generativity group achieved greater declines in HbA_{1c}, which widened through the 10th measurement (mean 1,365 days) to an average of 8.5% compared with an average of 8.8% in the outreach group and 9.0% in the stabilization group ($P = .003$). Rates of emergency department and hospital visits were lower in the self-care generativity group.

CONCLUSIONS Practice-linked CHWs can sustainably engage vulnerable patients, helping them advance self-management goals in the context of formidable social disadvantage.

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INTRODUCTION

Chronic diseases are the leading cause of disability and mortality, accounting for 73% of deaths globally and 88% nationally (United States).¹ Burdens of chronic disease fall most heavily on socioeconomically disadvantaged populations, meaning that those with greatest need for care have the fewest resources.²

A prime example of the remarkable acceleration of chronic disease and associated disparities is type 2 diabetes mellitus (T2DM).³⁻⁵ US diabetes prevalence increased from less than 1% in 1958 to 11% in 2020,⁶ with increasingly steep social gradients in health.

Avoiding diabetes complications such as ischemic heart disease, renal insufficiency, and limb amputation is more likely if glycosylated hemoglobin, blood pressure, and serum lipids are controlled.⁷⁻¹⁰ Unfortunately, many patients living with social disadvantage fail to achieve targets for risk markers and suffer a disproportionate share of complications.¹¹⁻¹³

Successful management of T2DM requires patients to actively participate in their care, but their efforts are undermined by poverty, lack of insurance, or difficult home and neighborhood environments.¹⁴ Implementing self-care strategies is an important function of primary care that provides a platform for reaching populations across the socioeconomic spectrum.^{15,16} Clinicians, however, often lack effective systems to help patients thrive in difficult circumstances.¹⁷

In response, primary care practices have deployed new care models. A common strategy is to engage interdisciplinary teams, which may include nurse care managers, health educators, behavioral health clinicians, or community health workers (CHWs).¹⁸ A large body of literature supports the role of CHWs in chronic disease management, but the relatively short duration of randomized trials (typically 6-12 months) limits our understanding of longer-term outcomes.¹⁹ Importantly, the optimal design and duration of the role of CHWs in different practice and community contexts has yet to be established.^{20,21}

This cohort study evaluated 4-year outcomes of a primary care intervention for T2DM control in a predominantly Latine, inner-city cohort. The intervention emphasized skills for self-care in home and community, building trust with the health care team, and acknowledging the impact of living under conditions of imposed scarcity and injustice. This study assessed patients' engagement with the intervention and followed hemoglobin A_{1c} (HbA_{1c}) levels and needed urgent care, emergency department, or hospital visits over 4 years.

METHODS

Context

We evaluated a quality improvement initiative in a safety-net primary care practice in San Antonio, Texas.²² Launched in 2011 with financial support from Bexar County, Texas, the initiative transitioned in 2012 to Medicaid 1115 Waiver funding from the Center for Medicare and Medicaid Services to the Texas Department of Health and Human Services (DHHS). Medicaid 1115 Waivers allow organizations to use state Medicaid funds for specified activities beyond traditional medical services.^{23,24}

The Texas DHHS approved goal for this study was to decrease the proportion of patients with uncontrolled diabetes mellitus, defined as HbA_{1c} greater than 9% (National Quality Forum measure 0059²⁵). The Institutional Review Board at UT Health San Antonio reviewed the protocol, classifying it as quality improvement and therefore not human subjects research.

Intervention Design and Theory of Change

The intervention was designed as quality improvement, with pre and post analysis, and the ability to evolve through iterative learning. Its design drew on several theoretical frameworks relevant to primary care. Antonovsky's concept of salutogenesis²⁶ asserts healthy people live lives that are comprehensible, manageable, and meaningful. A meaningful clinical encounter connects with a person's sense of purpose. From Human Development economics,²⁷⁻²⁹ we identified a core goal of expanding people's feasible opportunities to be and do the things they value. And drawing on Freire,³⁰ we placed trust at the center of transformative human interactions, while acknowledging the importance of naming past injustices. The [Supplemental Appendix](#) contains additional notes on the framework.

Setting and Participants

The study took place in San Antonio, Texas, where 15.5% of 1.56 million residents have been diagnosed with diabetes mellitus³¹ with prevalence varying threefold across income and education strata. Among the 10,000 patients in the Family and Community Medicine practice, point-in-time estimates identified approximately 2,500 with T2DM. Resident and faculty physicians practice alongside nurse care managers, behavioral health consultants, clinical pharmacists, and medical assistants who participate in care management activities. These professionals are available to both clinicians and CHWs.

We identified potential participants from a practice registry of patients with T2DM, listing those with HbA_{1c} of 9% or higher, and accepted other clinicians' referrals of patients having difficulty controlling their diabetes. From October 1, 2013 through September 30, 2017, of the 8,647 patients in our diabetes registry we identified 1,270 eligible patients who agreed to meet with a CHW. We excluded 237 patients who received only brief, task-oriented assistance (eg, scheduling an appointment), and 47 patients who did not have a period of care recorded at disenrollment, or had HbA_{1c} less than 6.5% at baseline, or no HbA_{1c} results post baseline. This yielded a cohort of 986 people. For patients referred more than once during the 4 years (n = 34), we only included data from their last enrollment.

Initial meetings with CHWs occurred at patients' homes, the practice, or another venue chosen by the patient. CHWs then engaged patients in a series of face-to-face meetings we called *Nosotros* ["we"] events, designed to foster trust and patient progress by iteratively cycling through 4 questions: What do we want? Why do we want it? What do we do? What do we get?

The first 2 questions focus on patients' desired outcomes and motivation. The second 2 questions establish a course of action and its link to desired outcomes. Patients' goals could be disease specific ("I don't want to end up on dialysis") or more general ("I need a part-time job to help pay for groceries and meds.") Questions are posed in the first-person plural to emphasize commitment to the *Nosotros* from both patient and CHW.

Patients' intermediate goals were framed in a rubric, the 6-piece puzzle ([Supplemental Appendix](#)), which includes healthy food, sufficient activity, appropriate medication use, active participation in health care, understanding the numbers measuring self-management success, and developing trust in key partners. Assessing practical opportunities for healthy behaviors is a starting point for planning change.

Community health workers were not limited to assisting patients with their diabetes management and engaged help as needed for other patient concerns. For instance, CHWs were able to pass patient concerns to the care team regarding other unresolved health or social issues.

Patients and CHWs negotiated their encounter frequency based on patients' needs. To describe patients'

trajectories, CHWs conceptualized 3 periods of care, each with observable behavioral end points that were prospectively assigned by the CHWs. The periods of care were: (1) outreach where the patient and CHW agreed to meet face-to-face; (2) stabilization in which the CHW and patient identified and addressed barriers to self-care; and (3) self-care generativity in which the patients displayed motivation for self-care and demonstrated the skills to manage diabetes in their home (Table 1). These activities often had an unexpected, original nature transcending external advice. Community health workers planned to work with patients for 12 weeks, though in practice the range was flexible. The CHWs classified patients' progress through the 3 care periods in real time.

Community health workers were trained by a physician (C.G.S.) with extensive experience working with CHWs in different settings.³² The CHWs assembled weekly, for 1 half-day, for training, reflection, and program adaptations. They also met one-on-one with the physician (C.G.S.) weekly to formulate approaches to their patient panel.

Program Evaluation

We examined process, clinical, and utilization outcomes for patients enrolled from October 1, 2013 through September 30, 2017, retaining the full cohort in the analytical data set.

To describe the features of self-care generativity, 3 study investigators reviewed the primary qualitative data from CHW narratives that signaled patients' progress to self-care generativity. Data on common themes was discussed to reach consensus and then an investigator checked back with CHWs to confirm working themes were congruent with CHWs' understanding. Investigators were blinded to HbA_{1c} values and health services outcomes while defining the periods of care variables. Once the 3 periods of care were operationally defined (Table 1), we assessed patients' progress through the periods and the relationship to diabetes control and health care events. No further revisions were made to the criteria for assigning patients to specific periods of care.

Process variables for each patient included the number of CHW encounters, the duration spent with a CHW, and CHWs' narrative observations of each encounter. The primary clinical outcome required for our Delivery System Reform Incentive Payment project was HbA_{1c} level less than 9%. Hemoglobin A_{1c} predicts microvascular complications with consequences for length and quality of life.³³ To quantify potentially

serious health events during follow-up, we also examined pre- and post-intervention trends in visits to urgent care, emergency departments, and hospitals.

Statistical Methods

In the quality improvement context, the timing of HbA_{1c} measurements was determined by clinicians rather than a study timetable. We examined HbA_{1c} trends averaged over sequential observations, 1st HbA_{1c}, 2nd HbA_{1c}, etc (measurement episodes) following each patient's enrollment with their CHW. [Supplemental Appendix](#) displays mean days elapsed from study entry for successive measurement episodes. In the analysis, patients appear only once and were assigned to the most advanced period of care cohort attained. To determine whether hierarchical models were needed to account for patient clustering within CHWs, we examined intraclass correlation coefficients (ICC), noting negligible level-2 variance (estimated ICC for HbA_{1c} was 0.00; for urgent care, 0.021; for emergency department, 0.005; and for hospital visit, 0.008).

We assessed between-group HbA_{1c} differences using repeated measures ANOVA with period of care as the between-group factor and HbA_{1c} assessments as the within-group repeated measure.

Count data for urgent care, emergency department, and hospital visits were markedly skewed with a predominance of zero values. A test of overdispersion for each health services variable in a Poisson distribution found greater variance than

Table 1. Periods of Care Definitions

Period	Goal	Duration	Behavioral Marker/ Definition of Success
Outreach	Engage patient	1 day to 7 weeks	Patient and CHW agree to meet face-to-face
Stabilization	Build trust, create alliance	Up to 12 weeks combined	Patient and CHW problem solve for obstacles to self-care
Self-care generativity	Patient commits to self-care	Up to 12 weeks combined	Patient plans self-care, progresses through self-care milestones

CHW = community health worker.

Table 2. Cohort Demographics and Baseline Hemoglobin A_{1c} Values

Characteristic	Total	Outreach	Stabilization	Self-Care Generativity
Participants, No. (%)	986 (100.0)	267 (27.1)	399 (40.5)	320 (32.4)
Female, No. (%)	605 (61.6)	163 (61.0)	223 (55.9)	219 (68.4)
Male, No. (%)	378 (38.4)	105 (39.3)	174 (43.6)	99 (30.9)
Age, y, mean (SD)	55.7 (10.8)	54.6 (11.4)	57.6 (10.0)	54.9 (10.9)
English preferred, %	60.4	62.9	64.2	53.8
Uninsured, % ^a	59.0	56.6	59.4	60.6
Undocumented status, %	11.0	10.0	8.0	16.0
Baseline HbA _{1c} , mean (SD)	10.3 (2.0)	10.5 (2.0)	10.1 (2.0)	10.4 (2.0)

HbA_{1c} = hemoglobin A_{1c}. ^a Includes participants covered by a Bexar County health care installment payment plan graduated by family size and income.

expected ($P < .001$). A negative binomial model (allowing the variance to be estimated separately from the mean) was a better fit than a zero-inflated model. We therefore applied negative binomial regressions to predict the number of health care visits for each period of care group in the 12 months following CHW intervention, adjusting for the count of health care visits in the previous 12 months. Models were adjusted for covariates that we expected a priori to be important predictors: age, sex, health insurance, immigrant status, and language preference.

RESULTS

Table 2 displays patient demographics. The 3 cohorts were well balanced with respect to insurance status and baseline HbA_{1c}. Patients in the stabilization group were slightly older. There were proportionately more females and undocumented persons in the self-care generativity group than the stabilization group. The self-care group had proportionately fewer participants with English as their primary language.

Differences in HbA_{1c} Over Time

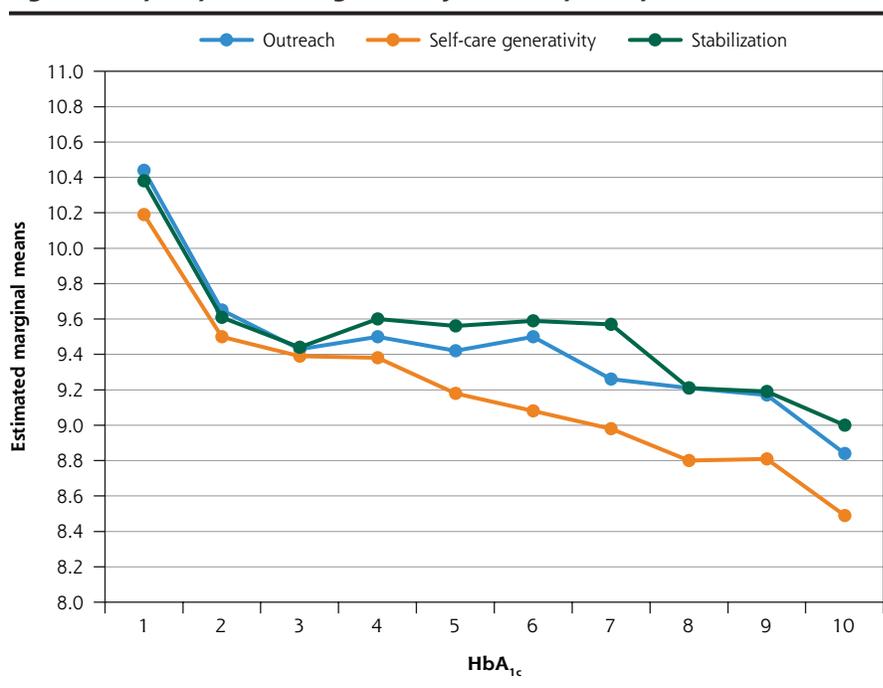
Mean HbA_{1c} at entry was between 10.1% and 10.5% in the 3 groups (P values for differences not significant). All 3 groups then demonstrated a significant drop in HbA_{1c} (Figure 1), without group differences, through the 4th HbA_{1c} measurement (mean follow-up 859 days).

Subsequently, the self-care group declined relative to the other groups ($P = .03$), reaching mean HbA_{1c} less than 9% by the 7th measurement (mean follow up 1,133 days). This trend continued through the 10th measurement ($P = .003$), where the HbA_{1c} in the self-care group continued to decline, reaching an average of 8.49% (mean follow up 1,365 days). Covariates in the model included age, sex, health insurance status, language preference, and immigration status. Figure 1 depicts the HbA_{1c} trends, with Table 3 listing sample sizes for sequential measurement episodes.

Health Care Utilization Outcomes (Table 4)

In our statistical model, we estimated separate negative binomial models for each health care outcome, by period of care group, adjusting for age, sex, insurance status, language preference, immigration status, and health care utilization in the 12 months before intervention. Exponentiating the estimated

Figure 1. Glycosylated hemoglobin trajectories by care periods.



HbA_{1c} = hemoglobin A_{1c}.

Note: Marginal means for HbA_{1c} are estimated for sequential measurement episodes during follow-up. Covariates appearing in the model were evaluated at age 55.7 and insurance 0.59. Difference between outreach and stabilization groups significant at $P < .001$ and between outreach and self-care generativity groups significant at $P < .002$.

Table 3. Sequential HbA_{1c} Measurement Episodes and Elapsed Days

Measurement Episode ^a	1	2	3	4	5	6	7	8	9
Number	877	827	714	613	496	402	330	248	182
Elapsed days, mean ^b	197	379	543	703	859	1,001	1,133	1,251	1,365

HbA_{1c} = hemoglobin A_{1c}.

^a Sequential glycosylated hemoglobin measurements during cohort observation period.

^b Mean elapsed days from first HbA_{1c} observation (time zero) across study cohort.

raw coefficients generated incidence-rate ratios (IRR, or incidence rates, in the case of the intercept). Figure 2 displays predicted counts of visits to urgent care, emergency department, and hospitals for each cohort.

In analyses adjusted for age, sex, health insurance status, immigrant status, language preference, and prior year utilization ([Supplemental Appendix](#)), IRR for hospital visits were twofold higher in the stabilization group than in self-care. Hospital visits in the outreach group were 6% higher than self-care, but this was not significant. Hospital visits were 90% higher in stabilization than in outreach ($P = .014$) (not shown in the [Supplemental Appendix](#)).

Compared with the self-care group, the average count of emergency department visits was 74% higher in the stabilization group ($P < .001$) and 31% higher in the outreach group ($P = .03$). There were no significant differences in IRRs across groups for urgent care visits.

Table 4. Health Care Utilization Outcomes for Negative Binomial Models

Characteristic	Urgent-Care Visits		Emergency Department Visits		Hospital Visits	
	Unadjusted, IRR (95% CI)	Adjusted, IRR (95% CI)	Unadjusted, IRR (95% CI)	Adjusted, IRR (95% CI)	Unadjusted, IRR (95% CI)	Adjusted, IRR (95% CI)
Intercept	0.68 (0.55-0.83)	0.45 (0.23-0.88)	0.38 (0.29-0.50)	0.31 (0.14-0.70)	0.15 (0.10-0.22)	0.07 (0.02-0.25)
Stabilization	1.22 (0.93-1.61)	1.11 (0.86-1.44)	2.32 (1.64-3.28) ^a	1.74 (1.27-2.39) ^a	2.10 (1.29-3.42) ^a	2.01 (1.25-3.23) ^a
Outreach	1.10 (0.81-1.48)	1.14 (0.86-1.52)	1.60 (1.10-2.38) ^a	1.31 (1.01-1.79) ^a	1.21 (0.69-2.11)	1.06 (0.60-1.85)
Self-care generativity	Reference	Reference	Reference	Reference	Reference	Reference
Emergency visits prior		...		1.49 (1.38-1.61) ^a		...
Hospital visits prior			2.07 (1.64-2.61) ^a
Urgent-care visits prior		1.38 (1.31-1.47) ^a	
Age		1.00 (0.99-1.01)		0.99 (0.98-1.01)		1.01 (0.99-1.03)
Sex		0.79 (0.63-1.00)		1.05 (0.80-1.36)		1.32 (0.89-1.98)
Insured		1.26 (1.00-1.59)		1.37 (1.04-1.80) ^a		1.39 (0.91-2.1)
Immigrant status		1.08 (0.70-1.65)		0.84 (0.51-1.39)		0.53 (0.25-1.11)
Language preference		1.09 (0.83-1.43)		1.14 (0.82-1.58)		1.23 (0.74-2.04)

IRR = incidence rate ratio.

^a Statistically significant result.

Note: Health care utilization outcomes—IRRs and 95% CIs for health care events over cohort follow-up, adjusted for age, sex, health insurance status, immigrant status, language preference, and prior year health care utilization. The model yields parameter estimates representing a log-count value (not shown) which are then used as an exponential of *e*, yielding an interpretable result (shown in table), representing the percentage of the original count units.

Quantifying Regression to the Mean

A major concern in observational studies is regression to the mean, the tendency for sampled point-in-time values to become less extreme on follow-up assessment.³⁴ To assess this, we analyzed a 5-year data set (that included the study years) of over 27,000 HbA_{1c} measurements from our practice. Among patients whose initial HbA_{1c} was greater than 9%—the eligibility cutoff for our study—and followed for intervals similar to our CHW intervention (6 to 36 months), absolute HbA_{1c} reductions averaged -0.055% by the 10th HbA_{1c} measurement. In comparison, the intervention group's decrease was -2% (absolute). Over shorter time frames, HbA_{1c} tended to decrease, but much less than we observed in our study population. For patients in the practice data set for 6-24 months prior to the start of this study, mean change in HbA_{1c} was -0.37% (absolute). Regression to the mean is therefore unlikely to account for a substantial fraction of the HbA_{1c} trends observed.

DISCUSSION

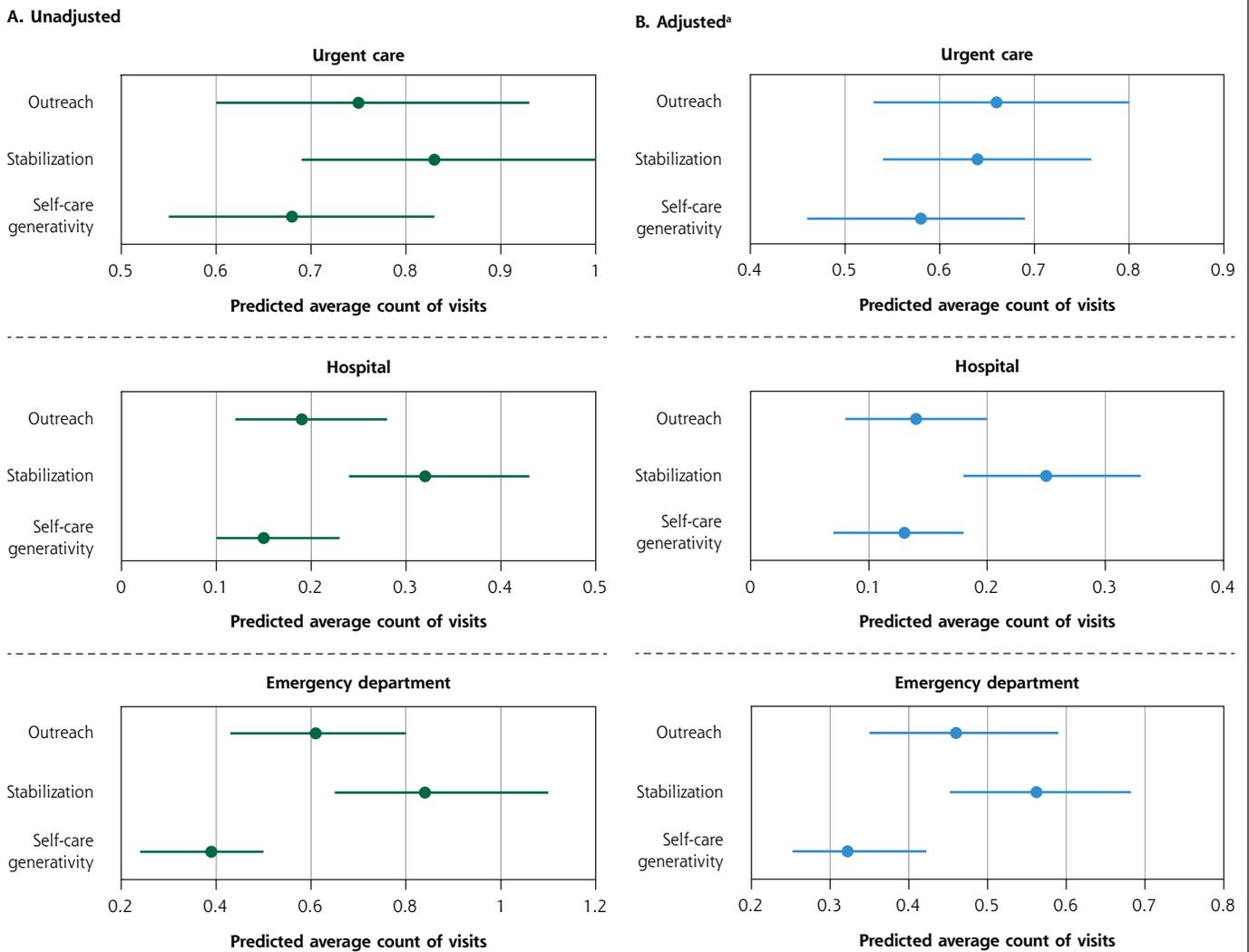
We evaluated program effects within a large, multi-year cohort of patients with uncontrolled T2DM. Community health workers were able to help 32% of patients attain a behaviorally defined level of self-management we named “self-care generativity” that was associated with sustained, clinically meaningful reductions in HbA_{1c} for up to 4 years, and a decreased risk of emergency department visits and hospitalization. Another 41% achieved an intermediate level of engagement and HbA_{1c} reduction, while 27% did not engage with the intervention.

The intervention was integrated within a safety-net primary care practice prepared to respond to patients' social adversity by integrating CHWs, behavioral health clinicians, nurse care managers, and medical assistants into population management. Community health workers' detailed understanding of patients' circumstances help to tailor their care rather than apply fixed interventions. That flexibility required a CHW workforce prepared to improvise in response to the challenging environments they navigated.

Our evaluation applied a naturalistic design, identifying patients with HbA_{1c} of 9% or more from a practice registry. Clinicians could also refer patients not making progress in glycemic control. The intervention evolved through continuous quality improvement as the team reviewed processes and outcomes.³⁵ Outcomes assessment relied on objective end points of HbA_{1c} values and health care events. Selection bias across the 3 cohorts at entry was mitigated by all included patients initially agreeing to work with a CHW.

Still, the findings must be interpreted in the context of a quality improvement intervention rather than a randomized trial.³⁶ Although the study population was not subject to the selection filter of agreeing to participate in a randomized controlled trial (RCT), our results could be influenced by the biases of nonrandomized intervention studies. Accepting help from a CHW may indicate general willingness to engage in health-promoting behaviors. Attrition over the 4-year study could have selected a population with greater commitment to engage with health care, or higher attrition may have occurred among patients experiencing poor outcomes. It should be noted, however, that we did not select patients

Figure 2. Predicted average count of health care visits, unadjusted and adjusted.



^a Values were adjusted for age, sex, health insurance status, and prior-year utilization.

based on a discrete event—such as a hospital visit—likely to mark a temporary decline in health from which recovery was likely.³⁷ Also, reviews comparing cohort studies with RCTs find relatively small differences in effect estimates, with the ratio of the odds ratios calculated to be 1.04 (95% CI, 0.89-1.21).³⁸

We attempted to quantify expected regression to the mean in longitudinal data from our patients with T2DM and elevated HbA_{1c}, and found it was 25% the magnitude of the observed main effect.

The time necessary to achieve clinically meaningful results is not surprising among patients facing multiple challenges, including unmet social needs. Time was needed for the practice to understand how to help specific patients and for patients to sustain new habits in old settings. CHWs met weekly to discuss continuous quality improvement and potential program adaptations.

This study adds to a growing body of literature on the value of CHWs in chronic disease management.³⁹ Systematic reviews of CHW interventions for T2DM have generally concluded that interventions are effective, often with modest effects and heterogeneity across studies. For example, a Task Force on Community Preventive Services review of 44 CHW interventions for diabetes estimated a median HbA_{1c} decrease of 0.49%, (interquartile range, -0.76 to -0.27) but median study duration was just 6-12 months, leaving questions about those interventions' durability.^{18,19,40,41} As most studies of CHW interventions report results from less than a year of observation, there may be insufficient time allotted for adaptive learning by CHWs. We observed positive effects up to 4 years.

Our reflections on what worked are consistent with a review of CHW interventions,¹⁹ emphasizing community embeddedness, supportive supervision, continuous education, cultural congruence,⁴² and adequate logistical support.

We add our perspective that the change agent is the sense-making collaboration between the CHW and patient. Also important was CHWs' coordination with practitioners, who benefitted from CHWs' observations of patients' homes, families, and neighborhoods, that provided the contextual details with the power to stall or support progress.⁴³

Despite promise, CHW programs can be difficult to maintain with time-limited funding. Programs' ability to demonstrate cost savings⁴⁴ may promote sustainability. After the Delivery System Reform Incentive Payment funding ended, our CHW program has been partially supported under pay-for-performance contracts with Medicaid and Medicare managed care payers. We would argue that investment in CHWs should not be strictly contingent on demonstrating savings. Community Health Workers help advance patients' health and promote health equity,⁴⁵ making them essential, fully integrated members of the primary care team. Community health workers leverage personal and professional experience to navigate social complexity, raising both practitioners' and patients' normative expectations for primary care practice.^{47,48}

CONCLUSIONS

We evaluated a multi-year intervention for uncontrolled T2DM in a safety-net primary care practice and found sustained HbA_{1c} reductions and fewer emergency department and hospital visits. These outcomes suggest a path to financial sustainability. Also, it is important to acknowledge the limits of applying individual-level interventions to health conditions whose origins lie in social injustices.^{50,51} Community-level change is necessary to address root causes.^{52,53}

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Key words: community health worker; primary care; self-management; trust; type 2 diabetes

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 [Supplemental materials](#)

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